DOCUMENT RESUME

ED 345 475 EC 301 237

AUTHOR Wilson, Leslie; And Others
TITLE Evaluation of Supported Placements in Integrated Community Environments Project (SPICE). Executive Summary of the Final Report.
INSTITUTION Corporate Alternatives, Inc., Springfield, IL.
SPONS AGENCY Illinois Planning Council on Developmental Disabilities, Springfield.
PUB DATE Oct 91
NOTE 30p.; For the Final Report, see EC 301 236.
PUB TYPE Reports - Evaluative/Feasibility (142)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Adults; Community Programs; *Deinstitutionalization (of Disabled); Group Homes; Independent Living; *Multiple Disabilities; Normalization (Handicapped); Nursing Homes; *Participant Satisfaction; Program Evaluation; *Quality of Life; *Severe Disabilities; *Social Integration

ABSTRACT

This executive summary presents highlights of a study which sought to determine whether participants in the Supported Placements in Integrated Community Environments project were better off after moving to community homes from intermediate care facilities and skilled nursing facilities, and to determine the variables that contribute to quality residential services for persons with developmental disabilities. The 37 people (ages 21-72) with severe or multiple disabilities and their families were interviewed while living in the nursing homes and then 9 to 10 months after moving to innovative one-person or two-person community integrated living arrangements. The executive summary describes the project's methodology and outlines the results in terms of adaptive behavior, problem behavior, service level, residential placement, daytime program, support services, social and leisure activities, consumer satisfaction pre and post movement, family satisfaction pre and post movement, residential review, and residential rates. The study found that participants are gaining skills, are exhibiting fewer problem behaviors, are much happier with their new homes, and have more opportunities to participate in the activities of community life. Their families have fewer concerns and are expressing greater satisfaction with their relatives' new homes. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Conducted for the
Illinois Planning Council
on Developmental Disabilities

by: Corporate Alternatives, inc. (CAi)

ED345475

Final Report

Evaluation of Supported Placements in Integrated Community Environments Project (SPICE)

October, 1991

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Chet Brandt
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Executive Summary

EC 301237

BEST COPY AVAILABLE

Executive Summary of the Final Report on the Evaluation of Supported Placements in Integrated Community Environments Project (SPICE)

Leslie Wilson
Project Director and Report Author

Cathy Edson Huffman
Project Assistant and Report Contributor

James Conroy
Conroy and Feinstein Associates
Statistical Analysis and Report Contributor

Conducted by:
Corporate Alternatives, inc. (CAi)
625 South College Street
Springfield, IL 62704
(217) 544-5687

Funded by:
The Illinois Planning Council on Developmental Disabilities

About This Study

This study was conducted by Corporate Alternatives, inc. (CAi) and funded by the Illinois Planning on Developmental Disabilities (IPCDD).

This evaluation project was designed to assess 37 persons who had moved from intermediate care facilities (ICFs) or skilled nursing facilities (SNFs) into innovative one or two person community integrated living arrangements (CILAs) as a result of the IPCDD funded Supported Placements in Integrated Community Environments (SPICE) project. The 37 persons who moved had severe or multiple disabilities, but did not require 24 hour nursing care.

The purpose of this evaluation was to determine whether people with severe disabilities were better off in small community residential settings and to identify the variables that contribute to quality residential services.

This study found that participants were happier with their community services, had more opportunities for integration, gained new skills and exhibited fewer challenging or problem behavior. Their families were also happier with their community services.

CAi would like to thank its expert interviewers:

George Bengel
Barry Berzy
Jane Elmore
Lark Kirchner
Donald St. Lawrence
Maggie Schaver
Russel Swirin
Mary Anne Willmore

CAi would also like to thank the ICFs and SNFs which permitted CAi's interviewers access to staff caring for individuals targeted to move and to their files, and the five SPICE community based provider agencies which also allowed CAi access to their staff and files. These providers cooperated with CAi in tracking the movement of individuals and without their cooperation, this study would not have been possible. They are:

Bethphage, Macomb
Jacksonville Association for Retarded Citizens, Jacksonville
United Cerebral Palsy, Mississippi Valley, Rock Island
United Cerebral Palsy, Land of Lincoln, Springfield
United Cerebral Palsy, Will County, Joliet

CAi would also like to thank the Illinois Planning Council on Developmental Disabilities

for choosing CAi to conduct this important assessment of the SPICE project and Kathy Carmody, the director of the SPICE project, for her cooperation and assistance during this evaluation.

Most importantly, CAi would like to thank the persons with disabilities who participated in this study. Without theirs and their families' cooperation, it would not have been possible to prove the benefits community integrated living offers to all persons no matter how severe their disabilities.

Leslie Wilson
Project Director and Report Author

Table of Contents

Introduction 4

ICAP Results 8
- Adaptive Behavior Section 9
- Problem Behavior Index 13
- ICAP Service Level 14
- Residential Placement 16
- Daytime Program 16
- Support Services 17
- Social and Leisure Activities 18

Consumer Satisfaction Pre and Post Movement 19

Family Satisfaction Pre and Post Movement 21

Residential Review 24

Residential Rates 25

Overall Summary 27

Introduction

This evaluation of the Supported Placements in Integrated Community Environments (SPICE) was designed to analyze quality of life outcomes for 37 people who moved from intermediate care facilities (ICFs) or skilled nursing facilities (SNFs), often referred to as nursing homes, to innovative one or two-person community integrated living arrangements (CILAs). The ultimate goal of this research project was to determine if people with severe disabilities were better off in small community residential settings and to identify the variables that contribute to quality residential services.

This analysis had pre and post components. Persons with disabilities were assessed using the Inventory for Client and Agency Planning (ICAP) prior to their moves to the community residences and then between nine and 10 months after their moves to their new homes. Participants were interviewed about their satisfaction with the nursing homes in which they were living and after 9-10 months in their CILA, they were asked about their satisfaction with their new homes.

Families were also interviewed pre and post about their satisfaction with their relatives' residential services.

An evaluation of each community residence was conducted, as well, to identify variables that contribute to a quality home.

At the outset of this research project, CAi had proposed a matched comparison component of this evaluation. This required that persons who would stay in an ICF or SNF would be matched with the individuals who were moving to a community residence. Baseline data was gathered on 46 stayers using the ICAP at the same time persons who were moving were assessed. However, when the computer attempted to pair movers and stayers on the basis of IQ, sex, age, race and disabilities it was discovered that only five suitable matches could be made. As a result, the study's matched comparison component was eliminated and no further data was gathered on persons who were not moving to community residences.

Methodology

Consumer assessments using the Inventory for Client and Agency Planning (ICAP) were conducted before individuals left the ICF or SNF in which they were residing and then 9-10 months after the individual was living in his or new community integrated home.

The ICAP has 10 sections and provides demographic information, and data on an individual's functional limitations, ability to perform activities of daily living, behavior

exhibited which is considered socially inappropriate, current residential placement, daytime program, support services provided and social and leisure activities.

The ICAP's adaptive behavior section has 77 items that provide information on how well someone can perform the activities of daily living. This section is organized into four domains:

* Motor Skills: gross and fine motor skills;

* Social and communication skills: expressive verbal and nonverbal communication, receptive verbal and nonverbal communication, clarity of speech, ability to read and write, one-to-one interaction with peers and persons other than peers, participation in social activities, telephone use;

* Personal Living Skills: eating, dressing, toileting, personal hygiene, food preparation, domestic skills; and

* Community Living Skills: associating time with events and actions, numbers awareness, money handling, purchasing, movement and transportation, using clock or watch, domestic equipment usage, attention to task, remembering instructions and demonstrations, budgeting, scheduling.

The ICAP's problem behavior section has eight categories and assesses the severity and frequency of behavior considered inappropriate in the following areas:

* Hurtful to Self;
* Hurtful to Others;
* Destructive to Property;
* Disruptive Behavior;
* Unusual or Repetitive Habits;
* Socially Offensive Behavior;
* Withdrawal or Inattentive Behavior; and
* Uncooperative Behavior.

CAi hired and trained five interviewers, all professionals in the field of developmental disabilities with experience in residential services, to administer the ICAP and Consumer Surveys. ICAP interviews were conducted with residential program staff who were most familiar with an individual's behavior and daily living activities. Consumers' files were used to fill in the blanks and to provide the needed demographic data.

Consumers who were willing were interviewed about their satisfaction with their present residence using the "Consumer Interview and Observation" survey. The ICAP and consumer interviews were conducted at the residential site in a private location. Consumers were interviewed alone to maintain confidentiality unless they requested that

someone else be present.

Families who were willing and could be located were also interviewed by telephone during evening hours about their satisfaction with their relatives' residential services using the pre and post "Family Satisfaction Surveys". CAi hired and trained two master's level professionals to conduct the telephone surveys.

The consumer and family satisfaction surveys were developed by Leslie Wilson and James Conroy of Conroy and Feinstein Associates.

After the 37 persons moved to their community residences and resided there at least 9-10 months, Leslie Wilson, Cathy Edson Huffman and Donald St. Lawrence conducted residential site reviews to determine a community home's exemplary facets and situations of concern. The residential evaluation forms used assessed the following items:

* residential management
* reimbursement rates
* appearance
* location
* cleanliness
* staffing patterns
* staff morale
* hours worked
* starting wages
* staff longevity
* staff credentials and training
* behavior management
* consumer well-being and safety
* community integration opportunities
* consumers' self-determination
* consumers' rights and privacy

Based on this data, the residences were given a numerical score by averaging the ratings of 13 items: restrictiveness, physical quality, safety, integration, quality of staff/consumer interaction, training for residential supervisory staff, training for residential direct care staff, client services, behavior management techniques used, quality of direct care staff, quality of client files, quality of individual habilitation plans, and overall residential management.

Residences were also evaluated to determine whether the SPICE objectives were met and to identify barriers to their attainment.

(Please see copies of all instruments in the appendix of the full report.)

Reliability

To ascertain the competency of its interviewers and the reliability of the various components of the ICAP, CAi conducted an interrater reliability test. The ICAP was administered twice to eight consumers, two from four of the participating agencies, by two different interviewers within a relatively short period of time pre-movement.

Based on the interrating of 150 ICAP items, four interviewers administering eight ICAPs two times had an average agreement rating of 78.33 percent. Which means that for each of the 150 items rated there was exact agreement over 75 percent of the time. This is an excellent rating and illustrates the reliability of the ICAP and CAi's surveyors.

Executive Summary

ICAP RESULTS

Description of the 37 SPICE Participants

The 37 people participating in this study who moved from an intermediate care facility (ICF) or skilled nursing facility (SNF), often referred to as nursing homes, were 63 percent male and 35 percent female. They ranged in age from 21 to 72 years with 42.5 the average age of the 37 participants.

The ethnic background of the group was 84 percent white, 13 percent African American and three percent Oriental, Asian or Pacific Islander. No one was listed as Hispanic and all 37 individuals listed English as their "primary language understood."

Within this group of 37 people there were two married couples. For the first time in their married lives each couple was able to have a home where just the two of them lived with support. With regard to legal status, 62 percent were competent adults, 27 percent had a parent or relative as a guardian and 11 percent had a county or the state named as guardian.

Primary and Secondary Diagnoses

The primary diagnosis of this group of individuals was most often cerebral palsy (73 percent). The next most common condition was mental retardation (16 percent). Other conditions listed as primary were brain or neurological damage (five percent) and seizures (five percent).

Thirty percent of the 37 participants in this study had no mental retardation, 24 percent were mildly retarded, 24 percent had moderate retardation, eight percent were labeled severely mentally retarded and 14 percent were listed as "unknown."

Only two individuals had a hearing impairment but no one was listed as deaf. One individual was blind and three persons had some vision impairment.

Nearly everyone had seizures that were controlled or never experienced seizures. Of those who reported experiencing seizures only one individual had them monthly and one person had them less than monthly.

Health Needs

This group of 37 individuals was remarkably healthy, considering they lived in nursing facilities before moving to community homes. Seventy three

percent were reported to have "no limitation in daily activities" associated with health, 16 percent had "few or slight limitations," and eight percent had "many or significant limitations."

As a point of interest, prior to moving to a community home, it was reported that 27 of the 37 persons required the care of a nurse or physician less than monthly. Six persons were said to need care monthly, one was reported to need care weekly and two persons were said to need care daily, while one individual was listed as needing care with immediate 24-hour access.

After movement to the community not one of the same 37 persons was said to need the care of a nurse or a physician on a weekly or daily basis or with immediate 24-hour access. Only two of the 37 people were reported to require the care of a nurse or physician monthly. The other 35 people required medical attention less than monthly.

Medication Usage

Prior to movement to their community homes, many of the SPICE participants were receiving some type of medication with over a quarter receiving drugs for mood, anxiety, sleep or behavior.

After movement to the community, it appeared that SPICE participants required less medical care and fewer medications. However, over 27 percent (10 persons) remained on medication for mood, anxiety, sleep or behavior post movement despite the fact that only two persons in this group had a secondary diagnosis of mental illness and the average Problem Behavior Score was in the normal range before and after movement.

Use of Arms and Hands

Twelve people (32 percent) had no arm or hand limitations. The use of arms and hands was limited for 15 people (41 percent) while 10 people (27 percent) were somewhat limited.

Mobility

Ten of the 37 participants (27 percent) had no mobility limitations and were able to walk with or without aids such as walkers or crutches. Seventy three percent of the participants (27 individuals) were described as "usually in a wheelchair." However, no one in this group was "limited to bed most of the day" or "confined to bed for the entire day."

Adaptive Behavior Section

The ICAP's adaptive behavior section has 77 items that provide information on how well someone can perform the activities of daily living. This section

is organized into four domains:

* **Motor Skills**
* **Social and Communication Skills**
* **Personal Living Skills**
* **Community Living Skills**

The ICAP was administered twice to all 37 individuals: once while residing in the nursing homes and then 9-10 months after moving to their community homes. ICAP interviews were conducted with residential program staff who were most familiar with an individual's behavior and daily living activities. Consumers' files were used to fill in the blanks and to provide other data.

Interviewers were instructed to only give credit for tasks the respondent actually saw the individual perform.

The ICAP produces a raw and a domain score for each adaptive behavior section. For all domains, a value of 500 represents a performance level approximately equal to that of a child who has no disabilities and is 10 years and four months old (at the fifth grade level). The range of domain scores extends from a low of about 270 to a high of 569.

The ICAP also produces a broad independence score which is an overall combination score from the four adaptive behavior domains.

For purposes of this study, pre and post movement scores were compared to gain insight into changes, if any, that occurred after the 37 SPICE participants moved to the community.

Motor Skills Domain

As anticipated, the rate of motor skills change pre and post movement was not significant by paired t-test. Prior to movement, the 37 individuals assessed had an average raw score of 22.7 on the motor skills scale; after movement that score dropped slightly to 21.97. The average domain score pre movement was 383.41, post movement it decreased to 380.30.

This average score reflects that 27 (73 percent) of the 37 persons evaluated had cerebral palsy and were described as "usually in a wheelchair." The use of arms and hands was limited for 15 people (41 percent) and 10 persons (27 percent) were somewhat limited.

The ICAP's Motor Skills Domain rates such fine and gross motor skills as picking up small objects by hand, threading a sewing needle, climbing a six foot ladder, and walking up and down stairs. These are abilities that people with a neuromuscular disorder would have great difficulty mastering no matter where they lived. Since these individuals were unable to accomplish many of the rated tasks, their average domain score before and after movement remained static.

This result had no impact on these individuals' ability to successfully live in the community as reflected by their personal and community living skill development discussed later. The disability or its severity could not be altered, but with individually tailored supports the SPICE participants have become integrated, productive and independent.

Social and Communication Skills Domain

Prior to movement, the 37 individuals assessed had an average raw score of 40.19 on the social and communication skills scale; after movement that score rose slightly to 42.19. The average domain score pre movement was 469.11, post movement it incrementally increased to 473.41, an improvement of 4.3 points. The lowest possible score for this domain was 311; the highest 555.

The 37 individuals' scores ranged from a low of 428 to a high of 555 during the second round of data collection.

The increase of 4.3 points in the Social and Communication Skills Domain is not significant by paired t-test.

Thirty of the individuals assessed were able to speak with little or no difficulty, six persons used communication boards to communicate and one person used gestures. All 37 individuals understood English as their primary language.

In addition to communication skills, this domain also rates social skills.

From the results, we can conclude that the individuals in this group were and continue to be able to communicate well and to socialize appropriately no matter where they live.

Personal Living Skills Domain

SPICE participants gained 19.38 points on the personal living scale in just nine to 10 months after moving to their homes in the community. This increase is highly significant by paired t-test and is this group's greatest comparative gain (t=4.99, 36 df, p=.001).

The Personal Living Skills Domain rates such things as an individual's ability to pick up and eat food, dress him/herself, mix and cook simple foods such as scrambled eggs, soup or hamburgers, prepare a grocery list for at least six items, load and operate a washing machine, etc. The tasks are arranged in a continuum from the easiest to the most difficult.

Prior to movement to the community, SPICE participants had an average raw score of 25.78 on the personal living scale; after movement that score rose to 32.58. The average domain score pre movement was 434.16 and rose to 454.14 post movement. A maximum score on this scale would be 557; the lowest score is 332. The range of scores for this group post movement was 378 to 545.

This finding also demonstrates that after these individuals moved from congregate care facilities to less restrictive and more normalized community settings they gained skills essential for self care and independent living no matter how severe their disabilities.

While it can not be verified without further research, it can be theorized based on previous studies that SPICE participants will exercise more self-sufficiency as time goes by now that they've been given the opportunity.

Community Living Skills Domain

One of the most exciting results of this study was the SPICE participants' relatively high average score in community living skills post movement.

Prior to movement to the community, SPICE participants had a raw score of 26.19 on the community living scale; after movement that score rose to 30.65. The average domain score pre movement was 468.22; after 9-10 months in their community homes that score rose to 480.02, this group's highest score on any of the ICAP scales. (A perfect score on this scale would be 569; the lowest possible score is 312.)

This increase of 11.80 points is very significant by paired t-test (t=3.04, 36 df, p=.004).

This section of the ICAP tests such things as, "uses the words 'morning' and 'night' correctly," "buys items that cost at least twenty-five cents from a vending machine," "uses a watch or clock," "budgets money to cover expenses for at least one week" and "balances a checkbook monthly."

Given these results and more time in their community homes, there appears to be no limit to the number of community living tasks SPICE participants will master.

Broad Independence Score

The ICAP produces a broad independence score which is an overall combination score from the four adaptive behavior domains.

The SPICE participants made major gains in the Personal Living and Community Living Domains; their scores remained static in the Motor, Social and Communication Skills Domains.

The average Broad Independence Score for the 37 individuals rose from 438.86 pre movement to 447.05 post movement. This increase is highly significant by paired t-test (t=2.53, 36 df, p=.016).

Summary - Adaptive Behavior Section

The result of the ICAP's Adaptive Behavior Section for the 37 SPICE participants showed no gains in the areas of motor, or social and communication skills. As anticipated, movement to the community had no impact on these individuals' disabilities or their severity. In the area of social and communication skills, this group of 37 communicated well and had good social skills before and after movement.

This group made the greatest gains in the areas of personal living and community living. It appears that SPICE participants are truly excelling in these areas after only 9-10 months in their new homes. While it can not be verified without further research, it can be theorized based on previous studies that SPICE participants will exercise more self-sufficiency as time goes by now that they've been given the opportunity.

Problem Behavior Index

The ICAP's problem behavior section has eight categories and assesses the severity and frequency of behavior considered inappropriate.

Large negative scores indicate more serious problem behavior. A score near 0 is average. The following chart explains the meaning of the values given.

Problem Behavior Index Scores

Index Value	Level of Seriousness
+10 to -10	Normal
-11 to -20	Marginally Serious
-21 to -30	Moderately Serious
-31 to -40	Serious
-41 & below	Very Serious

The 37 SPICE participants exhibited few problem behaviors before and after movement. During both rounds of data collection their scores were in the normal range.

Pre movement the average score was -4.32. Post movement the number and frequency of problem behaviors exhibited declined even further to an average score of -2.97, which nearly achieves the usual criterion for significance (t=1.46, 36 df, p<.077).

The range of scores was from 0 to -18 pre movement; post movement the scores ranged from 0 to -19.

Summary - ICAP Problem Behavior Index

What these scores tell us is that this group of individuals rarely acted inappropriately while living in the nursing facilities. After movement to their community homes, the number and frequency of problem behaviors dropped even further after only 9-10 months.

In other similar research studies, problem behavior has sometimes escalated shortly after movement to the community due to the adjustment period that most of us experience when we change our surroundings.

This is not the case for the SPICE participants and says something about their desire and readiness to live in the community.

ICAP Service Level

The ICAP Service Level is a weighted combination of the overall broad independence scores from the four Adaptive Behavior Domains and the General Maladaptive Behavior Index score. The Adaptive score is weighted 70 percent and the General Maladaptive score is weighted 30 percent.

The ICAP produces a score which ranges from 0 to 100 and levels one to nine. The higher scores and levels reflect increased independence and decreased need for help, supervision or services.

Prior to movement to the community the average ICAP Service Level score for the 37 SPICE participants was 54.32. After movement the average score rose to 59.81, a ten percent increase of 5.49 points. This change is highly significant by paired t-test (t=3.40, 36 df, p=.002).

This represents a 10 percent gain in skills after movement to the community. When comparing the SPICE participants' growth to Conroy and Feinstein Associates' studies of individuals with disabilities using similar scales, the SPICE group exhibited greater development.

The ICAP service level average score pre movement was 5.05 which placed the SPICE participants at level 5, "Regular personal care and/or close supervision."

Post movement their average score was 5.57 which placed them between levels five and six. An interpretation of this score would be that these individuals still required some "regular personal care and/or supervision," but the intensity of that care and supervision had lessened after only 9-10 months in their community homes.

Residential Placement

The ICAP contains a section titled "Residential Placement." This section notes the current residence and asks the respondent, based on his/her knowledge of the individual served, to make a "recommended change [in residential service] within next the two years, if any."

Prior to movement all 37 individuals assessed (100 percent) were living in intermediate care nursing facilities or skilled nursing facilities.

Before movement, nursing home respondents were asked if they would suggest any residential service change for the SPICE participants they served. The nursing home respondents said there was no need for a change in residential service for 12 persons (32 percent). Their recommendation for five people (14 percent) was "other," for eight people (21 percent) they recommended "group residence with staff providing care supervision and training," for 11 people (30 percent) they recommended a "semi-independent unit with supervisory staff in the building," for one person (three percent) the recommendation was for "independent with regular home-based services or monitoring."

After movement 21 people (57 percent) were living in settings described as "independent with regular home based services or monitoring." Another eight (22 percent) were in settings called "semi-independent units with supervisory staff in building," six (16 percent) were in "group residences with staff providing care, supervision, and training," and 2 (five percent) were in settings described as "other."

It appears from the recommendations of nursing home respondents that the individuals for whom they worked were capable of far more independence then they anticipated.

Post movement community respondents were asked where they thought individuals they served should live in the next two years. Only three persons (8 percent) were recommended for a setting other than the one in which they were living. All three were recommended for more independent living: one from semi-independent to independent with assistance; and two individuals from independent with assistance to independent in their own homes or rental units.

Daytime Program

While the 37 SPICE participants resided in the nursing homes some of them attended some type of formal day program outside the facility. The ICAP section 'G' asks respondents to list what type of day program the individual attended.

After movement from the nursing homes to the community, the SPICE participants' day programs became more productive in nature. For instance, prior to movement 46 percent of individuals were in day activity centers where instruction is provided on personal, social and prevocational activities. After movement, 35 percent of the SPICE participants were attending a day activity center, a reduction of 11 percent. Prior to movement 30 percent of the SPICE participants were attending a work activity center where social AND vocational training is provided. After movement 54 percent of SPICE participants were going to a work activity center. Prior to movement, no one was in supported employment; after movement one person had a supported job.

There were many recommendations for change in day programs after persons moved to the community. For 23 persons (62 percent) there were no changes recommended, but for the other 38 percent, supported or competitive employment was recommended for all but one person.

It is important to note that if change was advocated, community respondents recommended that SPICE participants move to more integrated, productive types of daytime activities with the exception of one case.

Support Services

The ICAP asks respondents to list the various types of support services presently being used by the persons for whom they are replying. The second part of this two part question asks the respondent to state which if any support services the individual is not using, but for which an "evaluation is needed."

Again the decrease in the perceived need for specialized medical services becomes apparent. Before movement, nursing home respondents truly believed that 13 SPICE participants (35 percent) needed either specialized medical or nursing care and that three persons (8.1 percent) required specialized nutrition or dietary services. That was a valid response since the persons for whom they were providing services were living in 'nursing' homes. After movement no one was using specialized nutrition services or medical or nursing care, although two people were recommended for evaluations.

After movement to the community the support services used became less medical in nature and more community based. For example, prior to movement, only one person was using home based support services. After movement that number rose to 14. Only two people had a vocational evaluation pre movement; after movement 10 people had a vocational

evaluation and three persons were recommended for such an evaluation by community respondents. Prior to movement nursing home respondents did recommend that 10 persons have a vocational evaluation. In the area of therapies, pre movement 16 people were receiving some type of therapy, i.e. occupational, physical or speech. After movement, 20 persons were receiving such therapy.

While residing in the nursing homes, 30 persons (81.1 percent) had case managers. After movement, 29 persons (78.4 percent) had case managers. This is a curious reduction in case management services and may be related to the time lag in assigning case managers when there is a major change in program. Community respondents did recommend that five SPICE participants be evaluated for case management services.

While the majority (54 percent) of SPICE participants now living in the community appear to need no additional services, 17 persons (46 percent) were recommended for various services, including case management (13.5 percent).

Social and Leisure Activities

This ICAP section asks questions related to SPICE participants' social and leisure activities and is again a two part question since it also asks respondents to list "factors limiting social activities."

Before and after movement, respondents checked all the various social and leisure activities in which each SPICE participant took part within the last month.

The number of persons participating in monthly social and leisure activities during a 30 day period made a dramatic increase once SPICE participants moved to the community. For example, in just 9-10 months, the number of persons visiting "with family and neighbors outside the residence" doubled. Other dramatic increases occurred in the areas of "shopping or out to eat" which jumped from 22 individuals participating in such activities (59.5 percent) to 36 persons (97.3 percent) and telephone use which went from 21 individuals using the phone at least once during the month (56.8 percent) to 30 persons (81.1 percent). The increase in telephone usage is also related to the availability of a phone. In the nursing homes, there are few phones available for many people. Once SPICE participants moved to the community, they had almost unlimited access to the phones in their residences.

After movement, almost every person was participating in some type of outside social or recreational ventures and more individuals were engaging

in hobbies or other personal leisure activities.

The second part of this question asked respondents to check all applicable "factors limiting social activities."

Fewer people experienced hurdles to social activities once they moved to the community while the number of persons not interested in participating before movement remained the same after movement. Again, nursing home personnel overrated health problems which were perceived to be an impediment to social activities for seven people pre movement, but disappeared for everyone post movement. The number of persons limited due to behavior problems also dropped from two individuals pre movement to one person post movement. Interestingly, the lack of money became a greater hurdle for people after movement than it was before. Perhaps this is due to increased opportunities for spending on leisure and social activities and the minimal amount individuals are permitted to keep for spending money.

It appears that SPICE participants after only 9-10 months are enjoying their freedom and expressing their independence in all aspects of their lives including social and leisure functions.

Consumer Satisfaction Pre and Post Movement

Because any research project is incomplete without data on consumer satisfaction, CAi conducted pre movement and post movement interviews with those consumers who were willing and able to talk about their satisfaction with their residential program. The SPICE evaluation design called for these interviews to be completed at the time the ICAP was administered. The consumer interviews were always conducted in a private location with just the consumer and interviewer present, unless the consumer requested that someone else participate. This was done to assure confidentiality.

The consumer interview consists of 10 questions related to satisfaction with the individual's current residential program. (Please see copy of the "Consumer Interview and Observation" survey in the appendix of the full report.)

During the first round of data collection, 29 of the 37 consumers who were willing and able to respond were asked about their satisfaction with the intermediate care facility (ICF) or skilled nursing facility (SNF) in which they were living. These interviews were conducted between March 1989 and November 1989 by CAi's five interviewers.

Between April 1990 and March 1991, the 29 consumers interviewed before they moved were asked about their satisfaction with the community integrated living arrangement (CILA) in which they had moved to from their previous ICF or SNF placement. In addition, six movers who did not participate in the pre movement consumer satisfaction survey, were interviewed during the second round. Movers had lived in their CILAs 9-10 months before the CAi interviewer returned to gather the post movement data.

The number of consumers interviewed post movement is greater due to the fact that six individuals were not interviewed about their satisfaction with the nursing homes in which they lived before they moved. For this reason, all data is in percentage form so that the responses of the 29 consumers can be fairly compared to the 35.

One of the greatest measures of satisfaction is the question, "Do you like living here?" Prior to movement from the nursing homes, only 24.1 percent of the SPICE participants responded affirmatively. After movement 91.4 percent said 'yes'. Individuals responding to this question send a clear message: they prefer living in the community to residing in a nursing home.

When asked about the staff people who served them, the majority of consumers seemed to be pleased with these individuals pre and post movement, although a greater percentage (22.9 percent) of those living in the community were satisfied with staff working with them.

When asked whether they liked their fellow residents, there was greater dissatisfaction with their fellow residents while the consumers resided in nursing homes. This is not surprising. Because the numbers of people are much greater in a congregate care facility, there are more people to dislike. The community homes to which these respondents moved were limited to one or two people maximum. After movement 69.7 percent of those living in the community said they "liked their fellow roommates." Prior to movement only 27.6 percent responded affirmatively.

Perhaps the most striking result of this consumer survey is the response to the question, "Is there someplace else you would rather live?" While living in the nursing home 85.7 percent of the individuals surveyed said 'yes', with 10.7 percent of those interviewed stating they were unsure. Conversely, only 8.8 percent of those interviewed wanted to live someplace else after movement to the community, with 11.8 percent saying they were unsure.

At the end of the consumer survey there is a section titled "Consumer Observation." The instructions to interviewers is to observe and document

whether the person interviewed is dressed, clean and groomed appropriately. CAi's interviewers found that every person interviewed pre and post was dressed appropriately. However, interviewers did note that one fourth of those still residing in the nursing homes was not clean and groomed appropriately. After movement to community residences, only one person (2.9 percent) of those interviewed was found inappropriately groomed and not clean.

Summary - Consumer Satisfaction

The persons participating in the SPICE project send a clear message: they prefer community living to residing in an ICF or SNF. They are happier with the services, appear to like the staff people and their fellow residents better, and almost 80 percent say there is no place else they would rather live than their community homes. Their comments are especially revealing and depict a group of individuals thrilled with the freedom and comforts their new homes offer. (The full report contains touching comments, pre and post movement.) Their comments also prove that it is the simple things in life that count the most. As one individual remarked after being asked what made him happiest about his new home, "The shower is in the bathroom."

Family Satisfaction Pre and Post Movement

The personal success of most individuals is often inspired by their families. For this reason, a vital component of the SPICE project was the family satisfaction survey.

The SPICE family interviews were conducted by two human service professionals during evening hours by telephone. The number of families is fewer than the number of consumer participants since some families were unwilling to participate or could not be reached.

There were two family satisfaction surveys: a pre movement survey and a post movement survey. This was necessary since some questions changed when their relatives moved from the nursing homes to the community living arrangements. (See copies of "Family Satisfaction Surveys" in the appendix of the full report.)

Prior to their relatives' movement to the community, 22 families were interviewed. After their relatives moved to the community, 14 families were interviewed. The number of individuals post movement is fewer because surveyors were unable to reach eight families during the second round of data collection. For this reason, all data is in percentage form so the responses of the 22 families can be fairly compared to the 14.

Overall this was a mature group of respondents, with the greatest percentage of respondents in the 66-70 age range during both rounds of data collection.

Just as consumers were happier with their new homes, so were their relatives and guardians.

When asked post movement how they felt about their relatives' home, relatives responded positively to the community homes while well over the majority of families expressed dissatisfaction with the nursing homes in which their relatives resided. For example, pre movement only 36.4 percent of those responding said they were 'very satisfied' or 'satisfied' with the nursing homes in which their relatives resided. After movement to the community, 92.9 percent of those responding were 'very satisfied' or 'satisfied' with the community homes.

Before movement families expressed a high rate of dissatisfaction with the majority (over 59 percent) saying they were 'somewhat or very dissatisfied' with the nursing facility. Post movement only 7.1 percent of those interviewed said they were 'somewhat dissatisfied' with the community homes.

When asked to project their relatives' happiness with their residential placements, families believed their relatives were happier than they actually were with their nursing home experience. Prior to movement, families said 45.4 percent of their relatives were either 'very happy or happy' with the nursing homes. When consumer satisfaction data is reviewed, it shows that well over the majority of consumers were dissatisfied with the nursing homes in which they lived. For example, prior to movement only 24.1 percent said they liked where they lived.

However, after movement, families said 100 percent of their relatives were 'very happy or happy' with their community homes.

When asked whether they thought their relatives had learned new skills while living in the nursing homes, 18.2 percent of the families said 'yes, definitely' with the majority of families responding 'probably not' or 'definitely not' (68.2 percent). One family member commented, "They don't have programs or time to teach anything." Three persons (13.6 percent) were unsure.

Conversely, as families visited their relatives in their new homes, over 57 percent responded 'probably' or 'yes,definitely' when asked if their relatives had learned new skills. Over thirty five percent (five respondents) were

unsure and only 7.1 percent (one person) said 'definitely not'. These families were excited with their relatives' progress and wanted to talk about it. The full report lists many comments pre and post movement on the subject of skill development.

Families' satisfaction with staff in the community residences and in the nursing homes varied somewhat; however, neither group said they were 'very satisfied' with the staff at either location. Prior to movement 31.8 percent of families said they were 'somewhat satisfied', after movement 42.8 percent said they were 'somewhat satisfied' with staff in the community.

Families were also asked to rate their satisfaction with the management of the nursing home and then the community residence. Again, not one of the families said they were 'very, satisfied' with the management at either location. However, the percentage of 'somewhat satisfied' families was over twice as great once their relatives had moved to the community. For example, prior to movement only 22.7 percent of families interviewed were 'somewhat satisfied' with management. After movement to the community, the number jumped to 50 percent.

Families were emphatic about their desire to see their relatives live somewhere else prior to their movement to the community. While residing in the nursing homes, 81.8 percent said 'yes' there was someplace else they would like their relatives to live. After movement, 23.1 percent said they would like their relatives moved, a reduction of 58.7 percent.

Summary - Family Satisfaction

Families reflect their relatives' satisfaction with their community homes. They believe their relatives are happier with their SPICE homes (100 percent satisfaction) as compared to their nursing home experiences (45.4 percent satisfaction), the majority of respondents believe their relatives have learned new things in the community (57 percent) and that they can do more things on their own (64 percent).

While they displayed a notable increase in their satisfaction with the community residences' staff people, management and appearance, not one of the respondents said they were "very satisfied" with these issues. This may be related to the fact that the homes had only been in existence 9-10 months and had not yet stabilized.

When asked if they had concerns about where there relatives lived pre and post movement, families did a flip-flop: pre-movement 71.4 percent were

concerned and 28.6 were not; post movement 23.1 were concerned and 76.9 percent were not.

The data mirror a group of families who are pleased with their relatives' new homes. This satisfaction is most evident in their comments. The most touching of these was stated by a parent who said, "This has changed our whole lives. After all these years she is doing beautifully. It's like a miracle."

Residential Review

A consumer focused residential review was conducted as a part of this project to determine the overall quality of the individual homes in which SPICE participants lived.

This evaluation consisted of interviewers conducting on-site reviews of the 22 homes operated by the five SPICE providers while the persons who lived there were present. Only two interviewers were used. One interviewer evaluated 14 homes and one reviewed eight homes.

Both raters were trained in the same manner. They used a checklist that assisted them in gathering basic information that was broken down by area: general, training, things to look for, physical quality, special concerns, personnel, behavior management, medical records and client services. (Please see residential review packet in the appendices of the full report.)

To summarize their findings, the reviewers used the "SPICE Site Review" instrument that rated 13 items believed necessary for a quality community based residential program to be successful.

Each item was ranked on a 1-10 scale with 10 being the highest possible rating, 1.0 the lowest and 5.5 average.

The quality of the 22 SPICE homes was very high. The overall rankings for the five agencies ranged from 8.32 to 9.27.

In 1989-90, Corporate Alternatives, inc. (CAi) conducted a review of 20 residences around the state for the Illinois Planning Council on Developmental Disabilities (IPCDD) through its "Evaluation of Community Residential Programs and Technical Assistance to Enhance Quality" project. During this review a four member team used an instrument almost identical to the "SPICE Site Review" instrument. The only difference in the two instruments was that the degree of safety and the quality of individual habilitation plans (IHPs) were not rated during the first study.

While an exact comparison cannot be made due to the difference in personnel during the two studies, it is interesting to note a comparison of scores. Again, 22 SPICE homes were rated, while 20 were evaluated during the earlier study. The scores ranged from 1.0, the lowest, to 10 the highest. An average rating was a score of 5.5.

The individual home scores during the earlier project ranged from 2.0 to 10.0. The overall average for all 20 homes was 5.63.

The SPICE results are impressive by comparison. The individual home scores ranged from 7.62 to 9.38. The overall average for all 22 SPICE homes was 8.86.

In addition to analyzing the scores for each of the 22 homes and each agency, CAi also analyzed the range and average scores for each items on the "SPICE Site Review" instrument to get an idea of areas were SPICE providers excelled or had difficulty. From these results, it became apparent that SPICE providers, on the average, are excelling in all areas with the exception of training. Both training questions, one related to supervisory staff and the other to direct care staff, were rated lower than all other items, but still above average (5.95 for supervisory staff; 7.55 for direct care staff). The same result was evident in CAi's earlier project with providers in Illinois. They stated in most cases that there was not enough money to provide high quality training to residential staff.

Summary - Residential Review

SPICE agencies are doing an excellent job providing a consumer based, individually tailored program of residential services to the 37 individuals participating in this project. Their overall average score was 8.86 on a scale of 1-10 with 10 being the highest possible rating. Of the 13 areas evaluated, those that could use some improvement were training for residential direct care and supervisory staff.

Residential Rates

Not one of the homes evaluated served more than two people and in some cases, SPICE participants lived alone.

The average per person, per day reimbursement rate SPICE providers received for the 22 homes was $73.38. The rates ranged from $70.51 to $81.55.

Three SPICE providers said the actual cost of operating these homes was greater than what they were reimbursed. These costs were estimated by the provider and ranged from $73.46* to $124.27 per person, per day.

*This provider was paid several dollars less per day.

In addition to the information above provided in the aggregate, the full report contains an overview of each agency based on various questions asked about management and training issues and a description of the SPICE participants, their homes, recreational activities and services they receive.

Overall Summary

This study had two goals: to find out if SPICE participants were better off since moving to their community homes and to determine the variables that contribute to quality residential services for persons with developmental disabilities.

Since moving to the community SPICE participants are gaining skills, are exhibiting fewer problem behaviors, are much happier with their new homes and have more opportunities to participate in the activities of community life. Their daytime activities have become more productive and the support services they are using are less medical in nature and more community-based. Furthermore, their families have fewer concerns and are expressing greater satisfaction with their relatives' new homes.

SPICE participants are much better off as a result of movement to the community.

The variables that contribute to quality residential services are many of those that are embodied in the CILA philosophy and the SPICE project. On a scale of 1-10, with 10 being the highest possible score, the 22 SPICE homes overall average was 8.86. The scores ranged from a low of 7.62 to a high of 9.38.

While the quality of the homes was very high, problems do exist. Direct care staff turnover rates are high, their wages are low and training for direct care and supervisory staff is inadequate. Providers cite funding as the reason for the low wages and lack of training. Three out of five of the SPICE providers say the per person, per day cost of the SPICE homes exceeds their reimbursement for the services provided.

Despite these drawbacks, SPICE participants are thriving and relishing all the wonders and joys of community life. All those involved in the development and operation of this program are to be congratulated for their vision and ability to implement it. In the words of one of the parents, "SPICE looks like a dream come true."